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A STUDY OF DIAGNOSTIC SERVICES FOR BRAIN-INJURED CHILDREN.
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THE PURPOSES OF THIS STUDY WERE (1) TO INVESTIGATE THE EARLY RECOGNITION OF BRAIN INJURY SYMPTOMS BY PARENTS, (2) TO EXPLORE THE DIAGNOSTIC PROBLEMS AND HISTORIES OF BRAIN INJURED CHILDREN AND THEIR PARENTS, AND (3) TO REVIEW THE EXISTING AND NEEDED FACILITIES FOR BRAIN INJURED CHILDREN IN NEW JERSEY. IN 1964, A QUESTIONNAIRE ELICITING BIOGRAPHICAL DATA, MEDICAL HISTORY, ATTITUDES OF PARENTS AND SIBLINGS TOWARD THE BRAIN INJURED CHILD, AND THERAPEUTIC NEEDS WAS SENT TO ALL PARENTS WHO WERE MEMBERS OF THE NEW JERSEY ASSOCIATION FOR BRAIN-INJURED CHILDREN. THE 190 RETURNED QUESTIONNAIRES (55 PERCENT) PROVIDED INFORMATION ABOUT 137 BOYS AND 53 GIRLS, AGED 4 TO 21 YEARS. PARENTS WHO RETURNED QUESTIONNAIRES WERE ABOVE NEW JERSEY 'S AVERAGE IN EDUCATION, OCCUPATION, AND ECONOMIC STATUS. ANALYSIS REVEALED THAT THE BRAIN INJURED CHILDREN IN THE SAMPLE TENDED TO BE BORN TO OLDER WOMEN (OVER 30). SPEECH WAS THE MOST VISIBLE DISABILITY OF THESE CHILDREN, FOLLOWED BY FAULTY BABY PATTERNS, POOR COORDINATION, AND SLOW DEVELOPMENT IN GENERAL. MOST LEARNING DISABILITIES (85 PERCENT) WERE FIRST NOTED AT SCHOOL AGE AND OVER HALF OF THE CHILDREN WERE MULTIPLY HANDICAPPED. PARENTS MOST FREQUENTLY COMPLAINED ABOUT THEIR CHILDREN'S BEHAVIORAL PROBLEMS OF INABILITY TO RELATE TO THE ENVIRONMENT. NEARLY HALF OF THE PARENTS WERE DISSATISFIED WITH THE WAY THEIR DOCTORS PRESENTED THEIR DIAGNOSIS. THE INSTITUTE FOR HUMAN POTENTIAL AND OTHER CHILD GUIDANCE AND EVALUATION CENTERS HAD THE HIGHEST REPUTATIONS AMONG PARENTS. MOST OF THE PARENTS REPORTED TAKING AN ENCOURAGING ATTITUDE TOWARD THEIR CHILDREN AND HOPING THAT THE CHILDREN WOULD ADAPT TO THEIR DIFFICULTIES. IN ALL, 89 PERCENT OF THE CHILDREN WERE CONSIDERED BY THEIR PARENTS TO BE IN GOOD HEALTH, AND MOST OF THE SCHOOL AGED CHILDREN ATTENDED PUBLIC SCHOOLS. PARENTS FELT THE MOST IMPORTANT IMMEDIATE NEED OF THEIR CHILDREN WAS FOR SPECIAL CLASSES WITH TRAINED TEACHERS. ELEVEN REFERENCES ARE LISTED. TABLES AND FIGURES SHOW STATISTICAL INFORMATION OBTAINED FROM THE QUESTIONNAIRES. (JA)

APR 26 1967

A STUDY OF DIAGNOSTIC SERVICES FOR BRAIN-
INJURED CHILDREN

Erna Henne^ssy

This study has three major objectives: (1) to investigate the early recognition of brain injury symptoms by parents; (2) to explore the diagnostic histories and problems of brain-injured children and their parents; and (3) to review, in particular, existing and needed facilities for brain-injured children in New Jersey.

REVIEW OF THE LITERATURE

Few specific studies have been made on the diagnosis of the brain-injured child or his family relations. However, many investigations have examined parental attitudes and reactions with regard to other kinds of handicaps.

Boles (1959) compared sixty mothers of children with cerebral palsy with sixty mothers of normal children on feelings of anxiety, guilt, over-protectiveness, rejection, unrealistic attitudes, marital conflicts, and social withdrawal. His sample was subdivided to represent equally mothers of younger and older children and mothers of Catholic, Jewish, and Protestant faiths. On the basis of self-administered attitude questionnaires specifically designed for the study, mothers of cerebral palsied children proved to be more overprotective and had more marital conflicts. Mothers of older children in both the palsied and normal groups were more guilty, rejecting, and unrealistic. Mothers of younger cerebral palsied children were more withdrawn. Catholic mothers in both groups were more guilty, un-

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realistic, and socially withdrawn than Jewish mothers. Jewish mothers provide their children with significantly more social opportunities than did Catholic or Protestant mothers. Protestants were significantly less anxious than the Catholic or Jewish mothers.

In testing initial reactions of sixty-seven sets of parents to a diagnosis of mental retardation, Graliker, Parmelee, and Koch (1959) distinguished between objective and subjective reactions--that is, those based on the actual conditions presented by a retarded child as opposed to those which were primarily self-centered and arose from their feelings about the child. Objective reactions included concern with: physical problems of the child (e.g., whether the seizures could be stopped, or whether the child would improve if he could see better); the child's future; his need for schooling or institutional care; general problems of retardation; outright rejection of the diagnosis; and an active search for information about other parents who had faced similar concerns. Subjective reactions included: concern on the parent's part with finding out how and why such a thing could happen to them; frank rejection of the child with shame and guilt; embarrassment at the child's appearance; worry about how to tell relatives; or about the effect of the child on siblings and friends.

Nearly a third of the group rejected the diagnosis after a diagnostic "work-up" including tests and interpretation by the physician. For most parents acceptance of the diagnosis so absorbed their emotions, they could devote no attention to the problem of future plans for the child. The authors argue that doctors need not include comprehensive discussions of the whole problem upon first presenting their diagnosis, that parents

must be allowed some time to mobilize their feelings. Suggestions of joining parents groups were at first poorly received because such an action involved acceptance of the diagnosis. Yet a follow-up survey showed that twenty-two parents who initially rejected the diagnosis had accepted it within a period of six to twelve months, after sympathetic counseling sessions by a physician or social worker.

In another study, the same group of researchers, along with another investigator, obtained data about the attitudes of parents with retarded children with regard to diagnosis, care, and counseling. (Koch, Graliker, Sands, Parmelee; 1958.) In the areas of treatment and care, fifty-five percent of the parents were satisfied with the general practitioner, forty-seven per cent with the pediatrician.

Fifty-one per cent of the parents were dissatisfied with the pediatricians' diagnoses, feeling them inadequately trained. By contrast, only twenty-three per cent were dissatisfied with the general practitioner who seemed better able to understand the family. Criticisms against both were: "too rushed," "examination not thorough," "not interested in the child," "they were either too hesitant to make a diagnosis or too blunt," "rushed us into placement," "unfair in predicting future." (Pediatricians and general practitioners recommended placement in institutions or foster homes in fifty per cent of the cases, obstetricians in sixty-four per cent of the cases.)

All parents felt that the way they were told about their child was as important as what they were told. Also, since many of the children had multiple handicaps, parents sometimes became confused with contradictory counseling. The authors concluded that a central location for all reports

on a given child was necessary to coordinate a training program for the parents.

Another investigator (Barsch, 1961) asked how parents, after receiving the diagnosis, explained the problem to their own friends and neighbors. In this study of 119 children with organic damage, parents were asked to check the kinds of explanations they had made, how they felt about using the term brain-injured, and finally how their normal children explained their brain-damaged siblings to their peers.

It was found that parents used the term brain-injured freely unless the child's functioning level was near normal. When the child had minimal brain damage, his parents may say that they do not know why the child behaves as he does or that he has a speech problem or he will outgrow his unusual mannerisms. Some parents use the term cerebral palsy even if the child is not so diagnosed because this handicap has received more publicity and is more understandable. Siblings for the most part adopted the explanation given by the parents, but parents themselves were not concerned how their children explained the problem to their peers.

PROCEDURE AND SAMPLE

To elicit more detailed information about the attitudes of parents with brain-injured children, a specially designed questionnaire was sent in late spring, 1964, to all parents who were members of the New Jersey Association for Brain-Injured Children. The questionnaire asked for standard biographical data such as age, sex, number of children in family, and education, occupation, and income of the parents. Parents were asked to describe the early indications of learning disabilities, and their first reactions. They were

also asked for a history of the medical specialists consulted and of the diagnoses given, and for degrees of satisfaction with the diagnostic services they had utilized. Finally, a battery of questions probed the present circumstances of the child, the attitudes and behaviors of siblings and parents toward the child, and the present diagnostic and/or therapeutic needs as seen by the parents.

In all, one hundred and ninety schedules were returned, representing 55 per cent of the Association's parent-members. The questionnaires provided information about 137 boys and 53 girls, ranging in age from 4 to 21. (One 26-year-old was kept in the sample because of information about early diagnosis.)

The parents who returned the questionnaire were above average in education (23 per cent of the fathers and 7 per cent of the mothers had graduate work), in occupation (33 per cent of the fathers and 12 per cent of the mothers classified as professionals), and in economic status. (See Tables 1, 2, and 3, respectively.) In 1963, 23.9 per cent of New Jersey families had incomes of less than \$5,000, but only 7.3 per cent of our families were in that income group. Though the categories are not precisely comparable, in the same year, 29 per cent of New Jersey families had incomes of \$10,000 or over, while 44 per cent of families in this sample had incomes of \$11,000 or over.

Beck (1962) found the same patterns among families who used family agency services. Kelman talks of the implications of such results when he laments the fact that a large group of parents with handicapped children are ignored when we study only middle class parents (1964, p. 85):

TABLE 1

EDUCATIONAL LEVELS OF PARENTS

	8th Grade or less	Some H.S.	H. S. Grad.	Some College	College Grad.	Graduate Work	No Response	TOTAL
FATHER	6 (3%)	20 (11%)	40 (21%)	33 (17%)	42 (22%)	44 (23%)	5 (3%)	190
MOTHER	3 (2%)	11 (6%)	65 (34%)	51 (27%)	42 (22%)	14 (7%)	4 (2%)	190

TABLE 2

OCCUPATION OF PARENTS

	Large Business	Small Business	Professional	White Collar	Skilled Labor	Unskilled Labor	House- wife	No Response	TOTAL
7 (4%)	32 (17%)	62 (33%)	51 (27%)	25 (13%)	5 (3%)	8 (4%)	190		
2 (1%)	1 (0%)	22 (12%)	10 (5%)	2 (1%)	3 (2%)	137 (72%)	13 (7%)	190	

INCOME OF PARENTS BY PER CENT

Under \$5,000	7.3
\$5,001 - \$8,000	21.5
\$8,001 - \$11,000	22.1
\$11,001 - \$14,000	14.7
Over \$14,000	30.0
No Response	4.2

The failure of many families to present themselves at newly established treatment centers or to institutionalize their damaged children or even to join parent-sponsored organizations does not necessarily imply that a disorder has not been perceived or that family-coping techniques have not been challenged. It does suggest that there may be modes of family reactions to the presence of a brain-damaged child which may be different from the patterns demonstrated by those families upon whom the bulk of existing clinical and research observations have been done.

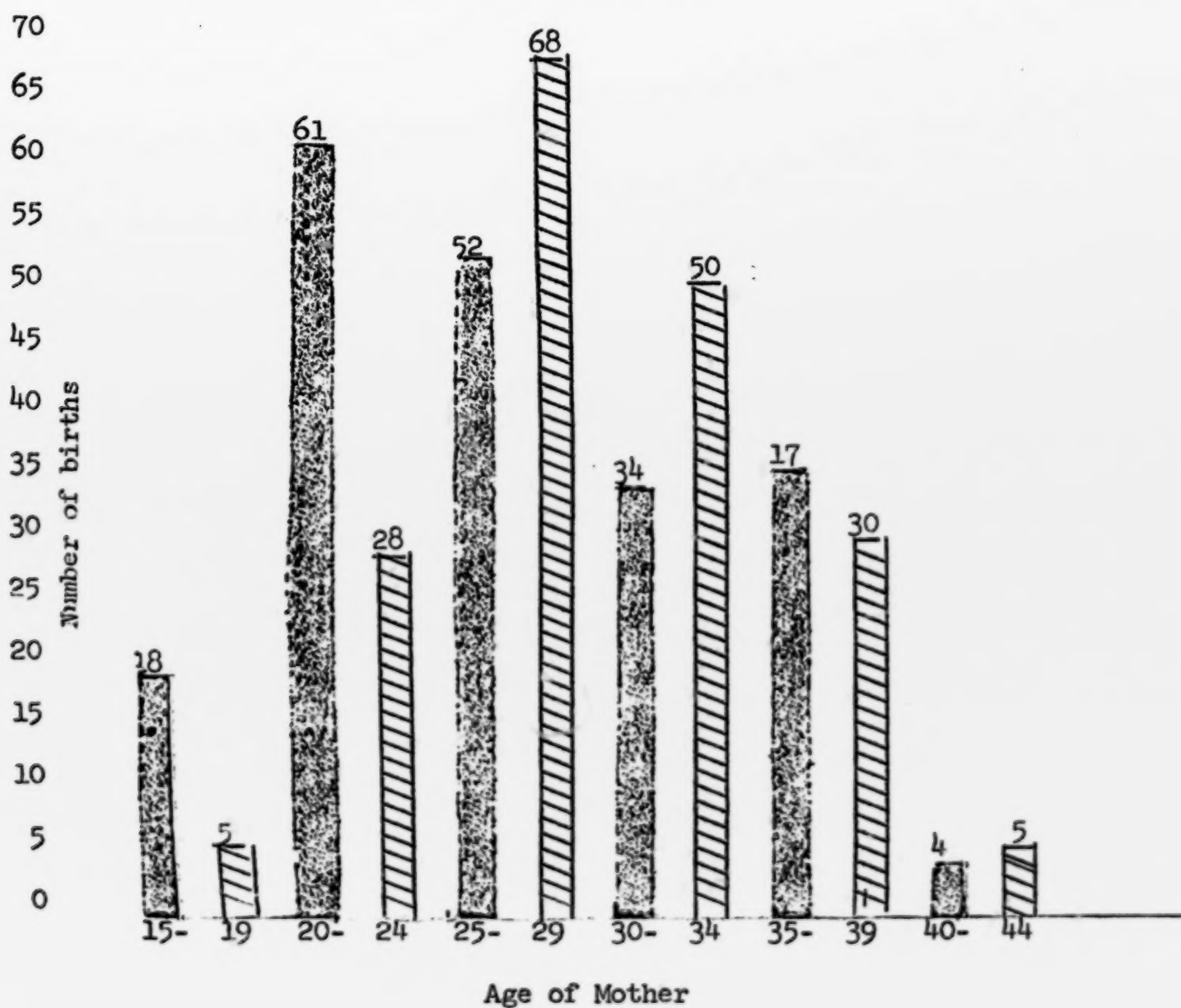
This study does not escape Kelman's strictures. It essentially is an investigation of attitudes and values held by middle and upper class parents.

If one assumes that the incidence of brain-damaged children is equal among parents of the three major religious faiths, then the data from the questionnaire indicates significant differences about the willingness of Protestants, Catholics, and Jews to join parents' groups--and/or respond to questionnaires of the sort used here. Catholics represent 39.2 per cent of the church members of New Jersey, but only 22.6 per cent of the respondents; Protestants represent 23.4 per cent of the state's church members but 42.1 per cent of the respondents; finally, while only 5.6 per cent of New Jersey residents are Jewish, they constitute 24.7 per cent of the respondents.¹

¹Statewide figures are percentages of adults who are church members, New Jersey Council of Churches, 1960. This statistic tends to understate Protestant affiliation.

It is also interesting that while 10.5 percent of the respondents were either of mixed religions or mentioned none, 31.8 per cent of New Jersey residents are religiously unaffiliated.

Figure 1: MOTHER'S AGE AT BRAIN-INJURED CHILD'S BIRTH COMPARED WITH EXPECTED BIRTHS BY AGE OF MOTHER IN NEW JERSEY



Expected Distribution
of 186 N.J. Live Births

Distribution of 186 BIC
Births by Age of Mother

Figure 1 shows the age of the mothers at the birth of their brain-injured child and compares this distribution with the expected births by age of New Jersey mothers in general. This figure strikingly illustrates the fact that brain-injured children tend to be born to older women. While all expected births peak at the 20-24 year category (61 out of 186 cases), only 28 mothers in our sample gave birth to brain-injured children in that age range. For mothers 30 to 39 years of age, incidents of brain-injured children's births are 60 per cent higher than would be expected from normal nativity statistics.

RESULTS

Early Development Characteristics and Present Problems

According to the questionnaire responses, speech (which represents the most highly integrated thought process of preschool children, involving as it does sensory input, processing, and monitoring of responses) is the most visible disability of a brain-injured child. Table 4 shows that speech difficulties noticed from the child's birth to one year mainly took the form of reports that the baby did not babble or utter any sounds at all. As the child reached two and three, the parents became more specific in their reactions, saying he could not string words together, made distortions and substitutions, and could not answer questions but only repeated them. In addition to speech problems, faulty baby patterns (see Table 4), poor coordination (which in the first year included the inability to hold a bottle, turn over, stand), and slow development in general were also recognized by parents.

TABLE 4

ABNORMAL BEHAVIOR AND AGE OF
CHILD WHEN PARENTS FIRST NOTED PECULIARITIES.
BY TYPE OF PECULIARITY

Characteristics	<u>Ages</u>									TOTAL
	Birth to 1 year	2	3	4	5	6	7	8	9	
Slow or garbled speech	6	31	32	8	12					89
Baby Patterns:										55
Placid-not able to nurse	10									
Poor sleeping habits	5	2								
Bedrocking-head banging	7									
Prolonged drooling	3	1								
Nausea-vomiting	3	1								
No infant games	3	1								
Anoxia	2									
General slow development	10	3	2	2						
Poor coordination	14	8	6	4	7	3		1	1	44
Hyperactivity	1	12	11	2	8	2				36
Irritability, temper tantrums	2	12	7	1	7	3	1			33
Learning disabilities		1	2	1	23					27
Convulsions	9	6	3		1	1				20
Distractibility, short attention		4	3	1	5	1		1		15
Sudden behavioral changes after disease or injury	7	2	1					1	2	13
Hearing disabilities	5	5	2							12
Visual disabilities	4	2	2	1						9
Withdrawal		1			1	3				5
TOTAL	91	92	71	20	64	13	1	3	3	358 ^a

^aSeveral parents noted more than one developmental abnormality.

The total of all first-noticed peculiarities drops at age 4, but rises at age 5 when the child goes to school. Parents report that 85 per cent of all learning disabilities were first discovered at this time. Distractability and hyperactivity are often first apparent when the child is placed in environments requiring concentration and longer attention.

Thirteen parents reported a sudden change in their child's abilities after a disease or injury (encephalitis, brain tumors, measles, roseola, automobile accidents and hydrocephaly) and attribute the change to this circumstance.

In the instances when parents noted visual disabilities, these were not described as partial blindness but as staring, poor focusing, eyes rotating outward, eyes that could not hold on an object, and eyes that did not follow sound.

A sizable number of parents mentioned (but without specifying the age level) that their child never cried when punished and never noticed pain unless it was very severe, indicating a high threshold of pain and suggesting the possibility that pain reactors may have been damaged.

Table 4 also shows that in general parents became aware of the disabilities of their children by discovering what Birch (1964) calls the "fact" of brain damage--that is, the physical results of dysfunction: slow speech, poor coordination, unusual baby patterns, convulsions, sudden changes after disease or injury, visual or hearing lags.

Table 5 indicates that parents now consider their greatest difficulties, for the most part (speech problems, which have dropped from first to sixth place, is an exception), to revolve around the behavioral adaptations their children have made to their injury.

TABLE 5

PROBLEMS PARENTS LIST AS MOST TROUBLESOME^a

Personality or Social Characteristics of Child	Ages of Children								Total
	4-5	6-7	8-9	10-11	12-13	14-15	16-17	18+	
Hyperactive, Impulsive	2	7	11	9	6	2			37
Hostile, Aggressive ^b	1	9	5	8	2	3	1		29
Withdrawn, Inferiority Feelings	1	3	11	3	4	4	1	1	28
Problems of Social Behavior (unspecified)	1	2	13	5	3	1	1		26
Irritable, Nervous		4	8	3	2		1	1	19
Speech Problems	1	1	4	2	3	1		1	13
Distractable	1	3	3	4	1				12
Frustrated ^b	1	2	3	4				1	11
Immature		1	1	3	2	2			9
Perseverative	1	1	3	1	1				7
None	1	9	11	8	4	1		1	35
No Response	4	4	4	6	2	2	3		25
TOTAL	14	46	77	56	30	16	7	5	251

^aThe figures represent the numbers of times the characteristics were mentioned by age groups.

^bAlthough frustration and aggression may be thought of as parts of the same emotion-behavior syndrome (see Dollard, 1939). I have not wished to go beyond the reports of my respondents. Unless they linked frustration with aggressive behavior, as they frequently did, I have regarded the two as separable personality characteristics.

Because this table was developed from responses to an open-ended question, the usual difficulties of interpretation were experienced. Many of the parents offered only tantalizingly general answers--for example, "doesn't get along well with his peers," or "has difficulty socializing," or "doesn't make friends easily." In such cases the responses have been placed in the category "Problems of Social Behavior (Unspecified)." Where more detail was given, it was possible to ascribe the difficulties of social relationship as being due to aggressiveness on the part of the child, to impulsive behavior, or to withdrawal.

If being withdrawn, hostile, and having problems of social behavior can all be considered as an inability to relate to one's environment, such a category, mentioned eighty-three times, represents the most frequent complaint made by parents about their children. At the other extreme, the ¹⁸thirty-five parents who listed no problems and the twenty-five who made no response may indicate that sixty parents find their children socially adjusted.

Reaction to Brain-Injured Child

Table 6 should be taken to represent not the initial responses of parents to a brain-injured child, but the responses of those who have accepted the diagnosis to the extent of joining an organization of parents who face comparable problems. (One hundred and seven of the one hundred and ninety respondents joined after they had a definite diagnosis of brain damage, forty-seven when they were hunting for help, eight when they first heard about the organization even though they had the diagnosis much sooner, and three when they suspected their child was different. Twenty-four parents did not indicate when they joined the Association.)

TABLE 6

PARENTAL ATTITUDES TOWARDS THE BRAIN-INJURED CHILD

Try to be encouraging at what he can do at his own level	166
Hope he can adapt to his difficulty	112
Find him pleasant to live with	95
Find him difficult to live with	84
Surprised he does so well in spite of brain injury	82
Hope he will outgrow his difficulty	76
Feel sorry for him	56
Think he could function normally if he really tried	15
Are trying to find out why this happened	11

For the most part these parents take an encouraging and realistic attitude, hoping that the child can adapt to his difficulty rather than wishing he would outgrow it. Whether a child is pleasant or difficult to live with would be directly related to the severity of his handicap. Only fifteen parents thought their child could function normally, in spite of the fact that many had repeatedly been told such things as "This child is spoiled, he needs a good slap," "You [the mother] are neurotic," "After all, not everyone is a genius," and "Give him time."

The question from which Table 7, which indicates the way parents describe the attitudes of siblings toward a brain-injured child, was made appears not to have tapped the real situation with much accuracy. The most common response probably was chosen because it seems the most socially acceptable. The reason for the high level of no response is variously accounted for by the fact that the brain-injured child was either much younger than other children in the family, many

of whom were away at college, or much older so that the siblings were in a sense the only children. No matter where a handicapped child ranks in a family in terms of age, he eventually comes to be treated as the youngest child because even younger siblings pass him in achievement.

TABLE 7
PARENTS' DESCRIPTION OF SIBLINGS' ATTITUDES
TOWARD BRAIN-INJURED CHILD

Siblings' Attitude	Brain-Injured Child's Rank in Family ^a								TOTAL
	Only Child	Oldest Child	Youngest Child	Second Child	Third Child	Fourth Child	Fifth Child	Sixth or more	
	14								14
Normal children treat brain injured sibling much as he does his other friends, with rough give and take.		46	43	21	13	1	2		126
Pity and try to help him.		4	8			1		1	14
Provoke him.		2	5	3					10
Ignore him.		2	2			1	1		6
Treats another way.		2							2
No response		5	7	3			1	2	18
TOTALS	14	61	65	27	13	3	4	3	190

^aThe age-position categories in Table 7 are not logically exclusive, but no child was placed in more than one category; thus the oldest child was always called the oldest regardless of whether he was the oldest of three children or the oldest of eight.

As might have been predicted from Barsch's study (1961: see Footnote 5), siblings reflect the parental attitudes of acceptance and encouragement.

Effect on Family

In response to the inquiry "What changes has this child made in your family life?", forty-one parents replied he had made no changes at all. Ninety-nine mentioned detrimental effects in the following order:

- a) Child's examination and care very expensive.
- b) He has limited or stopped all social activities of parents.
- c) Increased tension between parents, causing nervous breakdowns of either father or mother. (In four cases the mother gave as the reason for the parents' divorce the fact that the father did not accept the child.)
- d) Requires excessive amounts of mother's time.
- e) Meals, entertaining, garden decorations have been stripped to bare necessities.
- f) Limited the size of the family.
- g) "Chaos!! Have had to batten down the hatches."
- h) "Can't answer this. It would take a volume."

It is a common assumption that handicapped children create tragic crises in family organization. (See Farber, 1960.) Therefore, it is significant that thirty-seven parents noted that the brain-injured child made beneficial contributions to family life as well as to the parents' personality development. These positive effects were:

- a) "He has enriched our lives. We now take a broader view for all handicapped."
- b) "She has made us tolerant, understanding, firm, kind and better people."
- c) "We have learned to be flexible, less intent on perfection."
- d) "We are pleased with small accomplishments. He has given us a motive."
- e) Some parents have gone back to school to take up teaching of the handicapped.
- f) "We learned to love him and not hit him."

Parental Attitudes Towards Diagnostic Services

Table 8 presents data on the parents' rating of services used for diagnosis. The usefulness of this table is qualified by the fact that the questionnaire asked the parents to list the final or most helpful diagnosis in the same category, forcing many parents to use the rating of 1 for two different kinds of judgments. But the table does show how many visits the parents made² and gives general indications of satisfaction. If a rating of 1 or 2 is considered helpful and 3 and 4 not helpful, then parents made nearly as many unhelpful visits, 359, as they did rewarding ones, 403. It also indicates the many different sources where satisfactory diagnoses can be obtained--even a chiropractor got a rating from one family!

Eighty-seven parents thought the manner in which the diagnosis was given was appropriate, helpful, and clear. Seventy-two thought it inappropriate, rude, and blunt. Several noted some extreme cases of the latter: "The Doctor refused to give a final statement until threatened with possible lawsuit." "Are you kidding? Imagine nine years of psychologists." "They thought our only use was to transport the child and pay the bills."

The general tone of many dissatisfied parents, however, was that they wanted to know what was to be done for the child now that the diagnosis was made, and not getting answers to that question, they then became disgruntled at the diagnosis.

Sixty-nine said that all records concerning the child were kept in a central location and were accessible to other medical or school personnel, ninety-three said no such place was available, twelve didn't know, and fifteen made no response.

²Twelve parents did not respond to this question.

TABLE 8
PARENTS' RATING OF SERVICES
USED FOR DIAGNOSIS

Type of Service	Rating ^a				Total	% of 1 Responses
	1	2	3	4		
Neurologist	73	30	20	19	142	51
Psychologist	29	36	24	19	108	27
Guidance Centers, Psychiatric Clinics	18	3	4	8	33	54
Speech Clinics	15	15	15	15	60	25
Pediatricians, (Includes 4 Pediatric Neurosurgeons all in Col. 1.)	14	45	36	40	135	10.3
Child Evaluation Centers (Yale, California, Columbia)	13	5	0	1	19	68
Teachers, Principals, School Psychologists	9	30	31	23	93	9.7
Institute for Human Potential ^b	8	0	0	0	8	100
Diagnostic Clinics for the Mentally Retarded	7	11	10	4	32	21.8
Optometrist	7	8	10	15	40	17.5
Cerebral Palsy Clinics	6	7	7	9	29	20.6
Convulsive Disorder Clinics	2	0	3	0	5	40
General Practitioner	0	12	15	31	58	0
TOTAL	201	202	175	184	762	

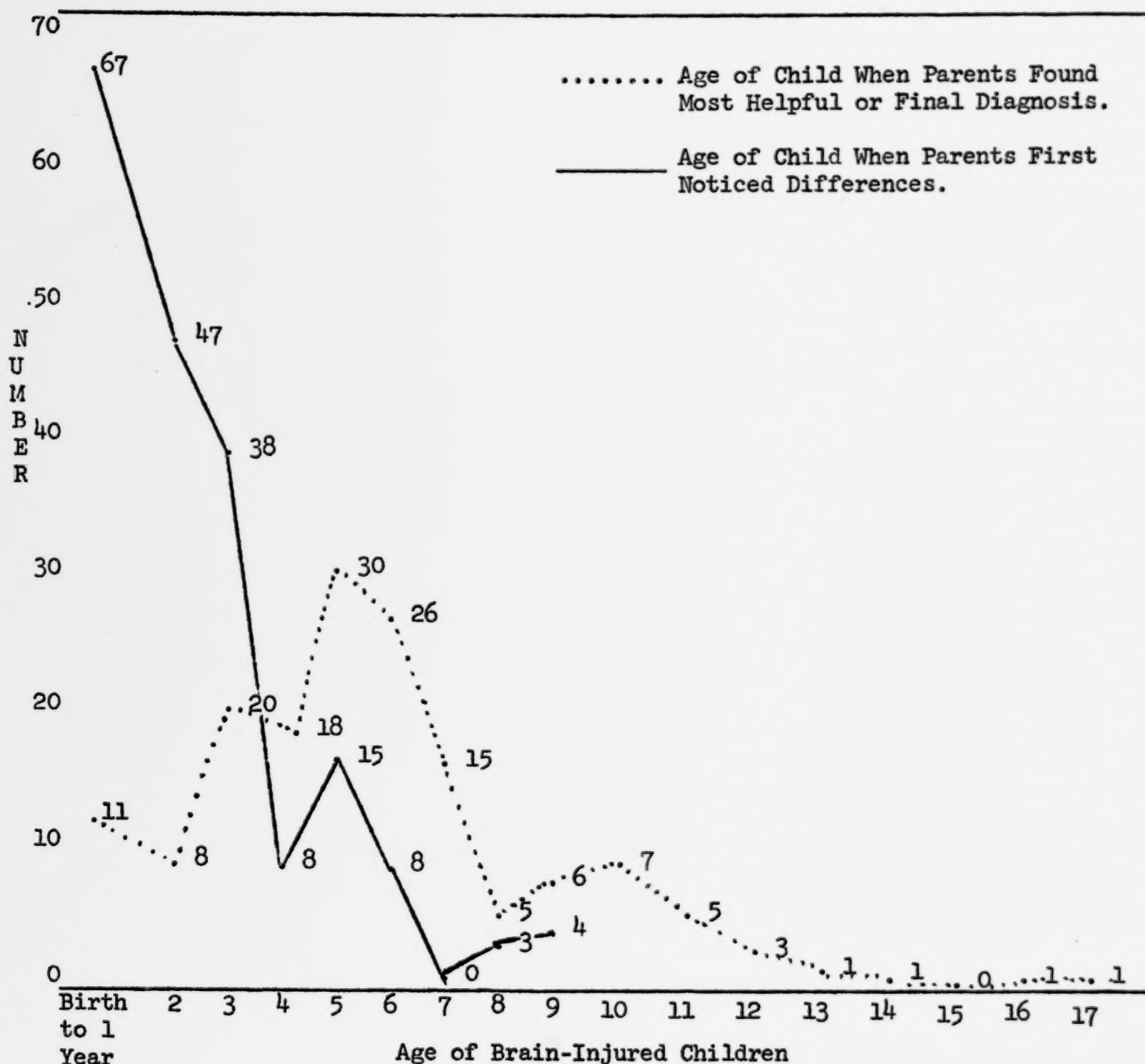
^a1--The final or most helpful diagnosis; 2--Led to the right diagnosis; 3--Not much help; 4--No help at all.

^bThe Institute for Human Potential, which is experimenting in re-training the brain, was kept in a separate category, even though the number was too small to be conclusive. This was done not only because of the 1 ratings the Institute received but because of the extra time parents took to describe in glowing terms the thorough examination the children received at the Institute and the improvement the parents saw in their children's progress after intensive treatment.

Figure 2 indicates the time lag between the first observation of abnormality and the final diagnosis. If it is true, as Denhoff says (1960) that "the longer it takes to learn about their children the greater the inner conflict about it" for the parent, then it must be detrimental to these parents who floundered for three and a half years before diagnosis finally overtook their observations.

Figure 2

TIME LAG BETWEEN PARENTS' AWARENESS OF
ABNORMALITIES AND FINAL DIAGNOSIS



The great number of parents who noticed differences from birth to one year may be those who have the children with the most profound handicaps. Since there was no place for parents to rate their child, whether severely or mildly damaged, this can only be a conjecture.

Between the ages of three and one half to six, however, all the children in the sample began nursery school, kindergarten, or first grade. This implies that at least then they were seen by people capable of making more or less professional judgments about and recommendations on learning difficulties or physical limitations. Consequently, diagnoses from this period is more discerning than earlier ones based only on parents' observations.

Present Status of Brain-Injured Children and Their Needs

Tables 9, 10, and 11 deal with the present circumstances and needs of the child and parent. (Table 11 is specifically concerned with the situation in the New Jersey location from which the sample came.) Eighty-nine per cent of the children are considered by their parents to be in good or excellent health, even though the brain damage has extended into intellectual, emotional or motor areas. These children attend classes. Only nine of the one hundred and eighty-five children remain at home, either with home instruction or no schooling. One hundred and thirty-three are enrolled in the public school system, in regular classes or in those for the brain injured, trainable, or retarded. On the other hand, that these children may not be placed according to their parents' satisfaction is reflected by the fact that one hundred and sixteen parents (see Table 11) feel the most important immediate need of their children is for more special classes with trained teachers. The desire for additional information concerning other parents, second in preference in the list of immediate needs, indicates the parents' willingness to confront and deal with the problems of their children.

TABLE 9
PARENTS' OPINION OF CHILD'S HEALTH BY DIAGNOSIS

Diagnosis	Health				Total
	Excellent	Good	Poor	No Response on Health	
Brain Injury	44	67	3	3	117
Cerebral Palsy	2	5	2		9
Convulsive	1	5	1		7
Mentally Retarded	2	4			6
Other (emotionally disturbed, aphasic, hydrocephalic, deaf)	5	11		1	17
Unknown		2			2
No response	6	16	3	7	32
Total	60	110	9	11	190

TABLE 10
EDUCATIONAL PLACEMENT FOR THE BRAIN INJURED CHILD
BY DIAGNOSIS

Diagnosis	EDUCATIONAL PLACEMENT										TOTAL
	Brain-Injured Classes	Regular Classes	Home Instruction	Train-able	Speech Therapy or School	Educable Mentally Retarded Classes	Private	Cerebral Palsy School	None	No Response	
Brain Injury	46	23	3	6	2	15	18	2	2		117
Cerebral Palsy	2	1			1	3	1	1			9
Convulsive	1	1		1			2		2		7
Mentally Retarded	1	1		1	1	2					6
Other	1	5	1			1	8			1	17
Unknown				1		1					2
No Response	7	6	1	1		6	3	4		4	32
Total	58	37	5	10	4	28	32	7	4	5	190

TABLE 11

IMMEDIATE NEEDS OF PARENTS AND BRAIN INJURED CHILDREN
BY GEOGRAPHICAL AREA

Geographical Area	Parent Information	Play Therapy on Week Ends	Trained Tutors	Special Classes with Trained Teachers	Need				
					Teenage Social Activities	Day Camp	Sleep Away Camp	Diagnostic Centers	None Other
Northern New Jersey Section N = 96	33	21	20	43	8	14	8		3 7
Suburban Essex Section N = 41	10	7	12	31	2	5	3	2	
Princeton Section N = 62	17	7	12	42	6	11	8	1	3
Total	60	35	44	116	16	30	19	3	10

DISCUSSION

This study provides clear indications that the first sign of brain injury to be noticed by parents is a variety of speech inadequacies. Alerted to the significance of these speech problems, parents themselves may help their children by simple phonetic exercises. They can also help them learn to listen carefully.

Further, that many parents listed beneficial social and familial consequences as well as the strengthening of their own personalities because they had a brain-injured child leads to the observation that the common view, which sees this circumstance as a more or less inevitable social tragedy for the family may be overdrawn. It is true that many parents traced marital and family strains to the presence of a brain-injured child, but a substantial number of these and other parents indicated that their experiences led them to wider understanding of the problems of other handicapped children and to practical social action to help meet these problems.

Nearly half of the parents who responded were dissatisfied with the way their doctors presented their diagnosis. Such criticisms strengthen the all-too-common view of the ineptitude of doctors in interpersonal relations. More than half of the parents indicated that records are not kept in the most useful and comprehensive way. Here too the medical profession may be lax: central record keeping and free transference of data are critical in diagnosis and therapy. (One is tempted to think that medical specialists resist the sharing of data and opinions because their confidence in their own diagnoses is not as high as they would like patients to believe.) Most significantly, the pediatricians and general practitioners who see the child early and often, and teachers who see the child at school age, come off badly in the eyes of the parents. (Pediatricians

may prefer not to make final diagnosis but rather advise parents to visit specialists, since in forty-five cases here his help led to the right diagnosis.)

Parents list 358 early learning irregularities, indicating that over half of the children are multiply handicapped. Multiple irregularities should provide multiple clues to diagnosticians. When a child has a single symptom of slow development (slow in sitting up or in walking or in talking), doctors and parents can afford to "wait and see." But if a child is slow in several areas, the doctor must be concerned and take steps for further diagnosis.

The Institute for Human Potential and other child evaluation and guidance centers have the highest reputation among the parents. Such centers provide clinic environments where many specialists work as teams with each child, and their success, as far as parents are concerned, may be interpreted in one of two ways. It may indeed be that multiply handicapped children are best served by teams of coordinated specialists who give comprehensive reports. On the other hand, parents may simply be overwhelmed by the total of so many authorities, ^{and} feel compelled to accept the diagnosis as conclusive. It seems clear, in any case, that the characteristics and worth of clinic centers deserve more study.

School administrators should also take note of the fact that most of the parents favor special classes over trained tutors. In the three sections of the Association (noted on Table 11), preference was more than two to one for special classes. The implication is clear. Parents want their brain-injured children to experience, insofar as possible, the normal daily routines of school-age children, including the trips to and from school, the peer-group relations of the classroom, and extracurricular activities. The tutor in the home, or after school, even when well trained and experienced, cannot supply the environment of a classroom.

It may be argued by professional educators that the one-to-one situation of tutor to child is ideal for learning, but the evidence is that parents want their children, as much as possible, to be in the mainstream of school life. Teachers and educators must bear in mind that 160 of these children are thought by their parents to be healthy--ranging from good to excellent.

It may be that schools should aim at cultivating more of the regular, normal, and "healthy" aspects of these children than emphasizing the features that set them apart from others.

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